


A black and white photograph of a young girl with braided hair, wearing a striped hospital gown, being held by a woman wearing a face mask. They are in a clinical setting, with a clock and medical equipment visible in the background. A red circular graphic is on the left side of the image.

BEYOND SURVIVAL

Recommendations for Transforming
Support Systems for Children & Youth
with Medical Complexity and Their
Families in British Columbia

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Beyond Survival: Recommendations for Transforming Support Systems for Children & Youth with Medical Complexity and Their Families in British Columbia

Prepared by BC Complex Kids Society as part of the 2024 Children and Youth with Support Needs (CYSN) Engagement Project, funded by the Ministry of Child and Family Development in BC

January 2025

The voices of a province-wide community



BC Complex Kids Society is a grassroots, family-led organization that brings families together to share knowledge, support each other and advocate for equitable support for our children with medical complexity (CMC). BCCK was formed in response to growing advocacy needs and the desire for families to come together as they navigate these complex support systems.

As the province of British Columbia advances its commitment to system reform, the BCCK has been invited to support engagement efforts and develop comprehensive recommendations to guide inter-ministerial policy aimed at meeting the needs of CMC and their families.

This document synthesizes insights gathered from a combination of community engagement, scientific evidence, advocacy efforts, and the lived experiences of individuals within our network. It offers a set of actionable recommendations, informed by years of dedicated work with a province-wide community, along with best practices identified globally. Over the past seven years, our organization has developed considerable expertise through research involvement, collaboration with policymakers, and contributions to provincial and federal government advisory councils. We also work in close allyship with other organizations to advocate for change.

As parent advocates, we are deeply committed to listening to the voices of our community, particularly through our online forum where daily lived experiences are shared. These voices, along with the personal experiences of our board members, are central to shaping the recommendations we put forward.

The focus for this document is primarily on community care needs, rather than acute and tertiary care – although we strongly support continued reforms to the hospital and specialized care system.

BC Complex Kids Society sought validation and feedback on this document by sharing the Executive Summary and Recommendations with 70 parents through a comprehensive survey, while eight parents reviewed the whole document and provided additional comments. In parallel, we engaged front-line professional and community partners, who also reviewed the document. Our professional reviewers, who work closely with some of the most marginalized families in our community, provided specific suggestions that strengthened the document and ensured its relevance. Families endorsed that it accurately reflects both their experiences and unmet needs, as well as the solutions that resonate with them.

This document reflects our collective efforts to amplify the voices of those directly affected and to ensure that our recommendations are grounded in both lived realities and scientific evidence.



"I think society as a whole believes that we are well resourced through government funding and that the 'burden' for me is my son. They have no idea. My son is not a burden at all to me. He is my reason for being. It is the system that forces me to fight every day to have his needs met. It is the system that wears me down, threatens my financial and emotional stability, and puts my health at risk, now and in the future."

— Family with CMC

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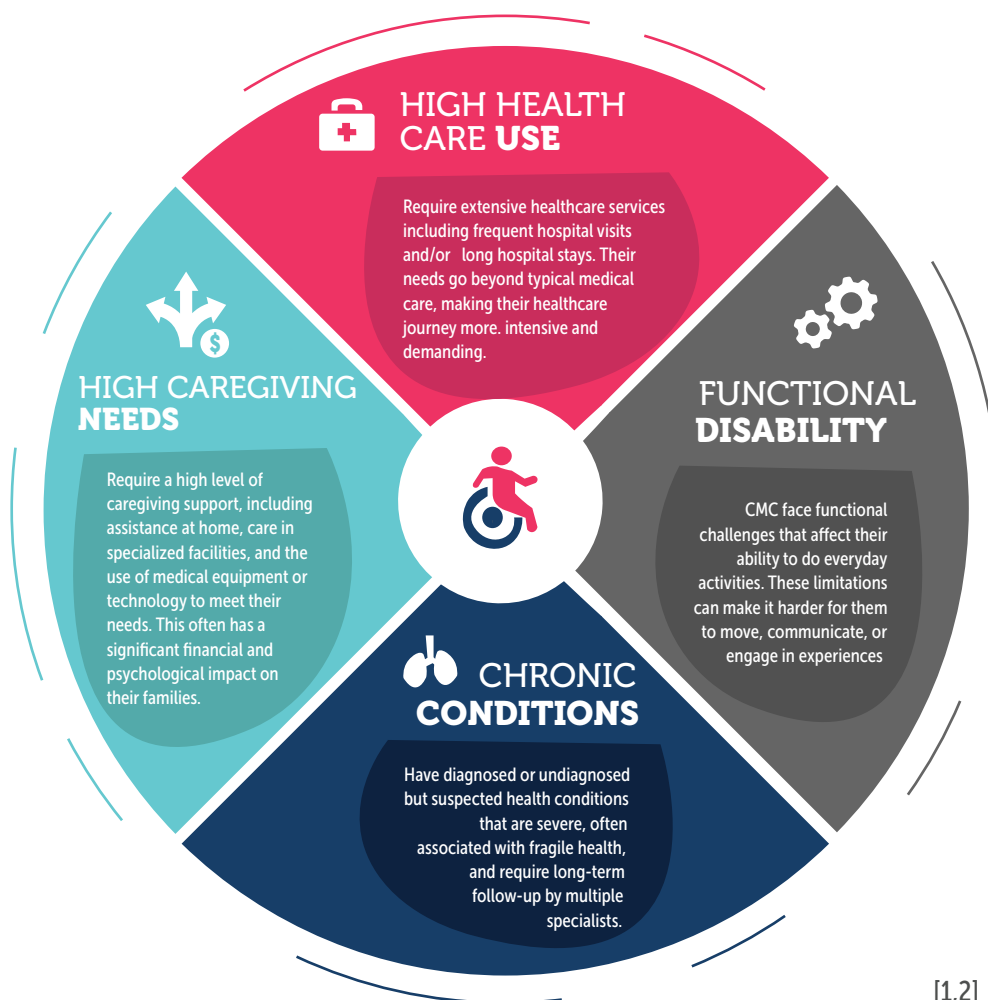
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Executive Summary

Context and Current Challenges

In British Columbia, more than 5,000 children with medical complexity (CMC) require intensive, specialized care due to chronic conditions and functional limitations/disability.

4 MAIN CHARACTERISTICS OF CHILDREN WITH MEDICAL COMPLEXITY



The population of children with medical complexity is very diverse, with an array of diagnoses and conditions that profoundly affect their life prognosis and day to day lives. Their common thread is that family caregivers – primarily mothers – support the high needs of their home lives as well as constant, complex navigation of the health, social, educational and financial support systems they need. Although advancements in medicine have improved the survival and quality of life of these children, systemic support has failed to keep pace, leaving families overwhelmed.

While children with medical complexity account for 0.8% of BC’s pediatric population, they represent a huge amount of healthcare costs and resources – national estimates suggest this cost is as high as 30%.

While programs like the At Home Program have been in place for decades to support families, these programs were developed in the late 1980s and have not adapted to rising costs or expanding needs. Today, families with children with medically complex conditions must navigate a fragmented, underfunded, confusing system, marked by geographic inequities and massive gaps in trauma-informed and family-centred care. Families bear an enormous, unsustainable financial and mental health burden.

KEY CHALLENGES IN THE CURRENT SUPPORT SYSTEM

Chronic Underfunding And Inequitable Resource Distribution

- Programs like Respite, Early Intervention and Supported Child Development face severe budget constraints, with long waitlists and inequitable access.
- Funding models fail to account for population growth, inflation, and diversity, resulting in inequitable resource distribution.

Geographic and Systemic Inequities in Access to Care

- Urban-centric services limit access for rural and remote families.
- Regional disparities exclude many children and families from support programs
- Families with multiple marginalizations experience compounded systemic inequities and barriers

Lack of Preventive Care

- Many families experience repeated hospital admissions and emergency room visits because of the lack of proactive or consistent care.

Administrative and Care Coordination Burdens

- Families must navigate fragmented systems, becoming de facto care coordinators, which is time-consuming and demoralizing.
- Lack of integrated cross-ministry collaboration compounds inefficiencies.

Gaps in Trauma-Informed and Family-Centred Care

- Bureaucratic processes overlook family well-being and perpetuate stress and inequity, especially for marginalized groups.
- Parents of CMC cannot access many of the same resources available to foster families, which forces some parents to place children in foster care.

Disconnected from the Financial Realities of Families

- Families bear unsustainable costs for home & vehicle modifications, medical equipment, care support.
- Many families experience lifelong financial struggles because of reduced workforce participation.



“The opportunity to pay caregivers, primarily mothers would be absolutely a vital and needed change. This is a huge missing gap that would drastically improve the well-being of families with complex needs children. I cannot emphasize this enough as parents are often the most skilled in caring for their children and are unable to return to work because of the complexity of needs.”

o Family with CMC

The Case for Change

This inefficient, fragmented system does not serve anyone well: resources are not used most effectively, children do not have access to the most meaningful opportunities for quality of life and health outcomes, and families experience unnecessary hardship and stress.

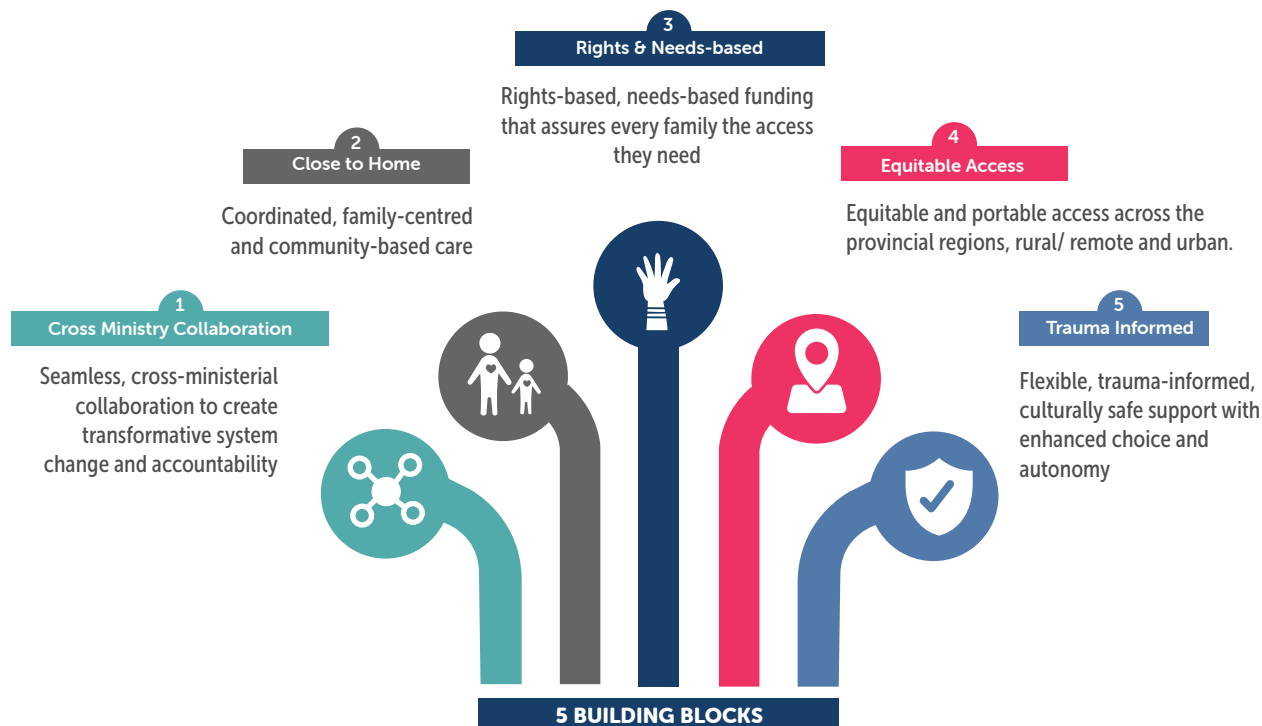
Families often find themselves in a constant battle for access to services, facing long waitlists, arbitrary eligibility criteria, and the stress of piecing together care from various programs that may or may not meet their child's evolving needs. These families experience inflexibility in a system that fails to adapt to their dynamic realities. The support they receive is often inconsistent, and families are left feeling unheard, unsupported and overwhelmed, despite their deep commitment to their child's well-being. This system is unsustainable: families need a holistic approach that considers not only the child's immediate care but also the emotional, financial, and social impact on the entire family.

The community of parents and professionals around BC Complex Kids Society recommends multiple changes to move toward a co-ordinated, holistic, fully funded and family-centred system. There are four broad goals: better health outcomes and quality of life for children, their siblings and parents; sustainable family life and increased workforce participation for parents; equitable access to care and better health for everyone across the province; and effective use of system resources through improved coordination and preventive care.



Building the System Children and Families Need

There are five essential building blocks for system reform:



1 Cross Ministry Collaboration: Seamless, cross-ministerial collaboration to create transformative system change and accountability.

- ➔ A coherent, cross-ministerial strategy for integrated, family-centred care and services across the province
- ➔ Co-designed systems with families to ensure systems change is respectful and responsive to their lived experiences, and inclusive from the start.
- ➔ Metrics, reporting and appeals processes based on family-defined outcomes to build trust and track system impact.

2 Close to Home: Coordinated, family-centred community-based care.

- ➔ Care coordination teams, to streamline navigation, care planning, and resource allocation, with children and families as partners in decision-making.
- ➔ Extended transition support to provide services for children with medical complexity up to age 25, aiding developmental transitions to adulthood.

3 Rights & Needs-based: Rights-based funding that assures every family the access they need.

- ➔ Needs-based, rights-based funding models that address disparities and inflation-adjusted costs.
- ➔ Comprehensive approach to supporting families with financial support for home and vehicle accessibility and with income support that acknowledges the labour of family caregivers.

“If different funding and oversight agencies could work together to provide the services and care needed it would be a better quality of care for our children. I would like changes made so that people with disabilities can access the care they need and to have more accountability for those who oversee the services and funding”

Family with CMC

4 Equitable Access: Equitable geographic accessibility

- ➔ Community-based services, close to home, to reduce reliance on urban-centered programs and ensure localized support.
- ➔ Funding must be equitable across the province and portable across regions

5 Trauma Informed: Flexible, trauma-informed, culturally safe practices

- ➔ Flexible practices that enable families the autonomy and freedom to make informed choices about the care their child receives enabling families to access support in a manner that fits their unique needs and circumstances.
- ➔ Trauma-informed and culturally competent practices that recognize that families come from diverse backgrounds and may have experienced historical or ongoing systems-based trauma.

To create the system needed by families and their children with medical complexity, we need long-term system change, built on these five principles. This includes investment in funding for health and education, commitment to equitable and inclusive funding and services across the province, workforce sustainability for the many health, education and social service professionals families rely on, and a revamping of the structures to support disability rights in services.

While long-term system transformation is underway, there are a multitude of specific changes that can be initiated immediately. These changes have been identified by the BC Complex Kids community as the most urgent changes that will make an immediate difference.

Acceleration Agenda

- ➔ Immediately invest in critical foundational supports that enable more equitable outcomes and inclusive access to care support, including therapy, education and child care.
- ➔ Increase financial support for families through pilot or enhanced programs for paid caregiving, respite support, accessible housing, equipment and accessible home and vehicle funding.
- ➔ Initiate rapid implementation of a new model of community based care coordination, in alignment with the planned BCCH Centre for Health Complexity, to immediately streamline support, reduce family burdens and support the allocation of tailored resources to families.

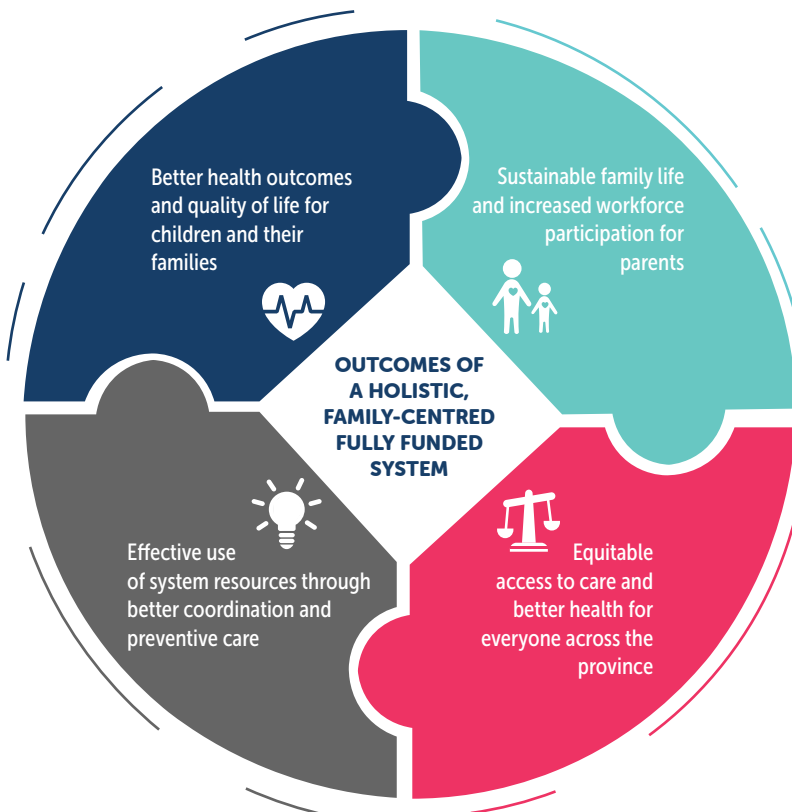


"When we moved from one urban community to another, it became one of the most stressful transitions we've ever faced. Despite the move being just a few kilometers, everything changed. We had a new school team, a new social worker, and we lost all our respite funding and Supported Child Development support, having to go back on waitlists for everything. It took the agency 8 months to put together a new nursing team for our son. For months, my son couldn't attend school, and I had to take six months off work to manage his care. It was financially draining for our family—I felt like I had moved to a completely different country."

— Family with CMC

Conclusion

Transitioning to a coordinated, proactive system will bridge critical gaps, reduce trauma, and improve outcomes for children with medical complexity and their families. By prioritizing adequate and equitable funding, family-centred services and rapid innovation, BC can create a resilient system that supports vulnerable populations while benefiting the broader community.



[IN BRIEF]

EXECUTIVE SUMMARY

The approximately 5000 children with medical complexity in BC represent nearly a third of the cost of pediatric health and social services in the province, but their needs are not being met by an underfunded, fragmented system.

The system does not support the best quality of life or health outcomes for children, access is inequitable across the province, and families have significant financial, emotional and health strain to try to support their children.

The community represented by BC Complex Kids recommends a reformed system that includes adequate and equitable funding, integrated, family-centred services, equitable geographic accessibility, extended transition support to the age of 25, trauma-informed and culturally safe practices, and accountability and transparency based on the outcomes meaningful to families and children with medical complexity.

Three changes that will make a profound difference can be implemented immediately: rapid implementation of community-based care coordination; pilot programs for paid caregiving, income support and funding for accessible homes and vehicles; and investments in the family-level supports that have been proven to make a difference.



Background and the Case for Change

SECTION 1

In this section, we describe the current experiences of families and children with medical complexity and outline the need for change.

Who Makes Up the Population of Children With Medical Complexity?

In British Columbia, at least 5,000 children – and possibly as many as 9,600 (3) – have complex medical needs, often referred to as children with medical complexity (CMC). This diverse group of children and youth require high levels of caregiving and support due to functional limitations/disability, chronic health conditions, and extensive use of healthcare services.

Thanks to advancements in medical care and technology, the population of children with medical complexity is evolving and growing (4). Preterm and medically fragile children who may not have survived two decades ago are now living into adulthood, often with greater functionality and quality of life.

What does it mean to be living with medical complexity?

The term “medical complexity” covers an incredibly diverse population of children and youth, who have a wide array of disabilities, medical fragility and conditions that affect their development, life prognosis and daily living in a multitude of ways. No two children with the same sets of conditions have the same life experience or function, and one of the markers of this population is that conditions frequently change.

Generally speaking, children with medical complexity may have a wide variety of diagnoses, including most commonly, cerebral palsy, rare genetic or neurodevelopmental conditions or chronic pain. Many of these children started life as fragile infants in the NICU, and throughout their lives, may experience feeding issues, pain and sleep issues, seizure disorders, behavioral complexities, multiple surgeries and physical and intellectual disabilities. Many are wheelchair users or require other mobility assistance; some are non-speaking or need augmented communication technology. Many experience cycles of intensive medical intervention, both in specialty healthcare and provided by family members. With the support of education assistants, a majority of children are able to go to school; while other families find that home learning programs work better for their children.



“It feels like I run a mini-ICU in my home. Boxes of medical supplies line my hallway closets, emails between therapists and specialists are ongoing, I give handover to the nurse that will tend to my daughter overnight. Alarms go off: reminding me to silence the feeding pump, check her heart rate, or determine if the oxygen concentrator needs to be turned up. I am constantly on alert for anything to happen – emergency bag ready to go by the front door. The door that has welcomed countless first responders over the years, to revitalize my child. Beyond her acute fragility is chronic joy within a child that goes to school, pesters her big brother and enjoys activities outside in the fresh air. We just want to give her the best life she can have. We can’t do it on our own though; it’s too much.”

o Family with CMC

The vast majority of children with medical complexity live with their families, and family members – primarily mothers – are their main caregivers. The lives of families with children with medical complexity are a blend of continual, frequently changing, caregiving against a backdrop of regular family life. Families are continually working to navigate the multitude of resources needed to provide the “6Fs” to their children: Functioning, Family, Fitness, Fun, Friends and Future (5). This labour frequently leaves families strained in many dimensions – financial, relational, and mental health for parents and the other children in the family.

As recently as the 1980s, children with complex disabilities were often institutionalized due to social stigma and lack of practical, financial and specialized support for families. During that time, families began to advocate strongly for the resources necessary to care for their children at home, resulting in the creation of the At Home Program (6). This groundbreaking program allowed families to access therapy, respite care, medical equipment, and supplies needed to support their children at home.

Number of Clients Served by At Home Program Over Time

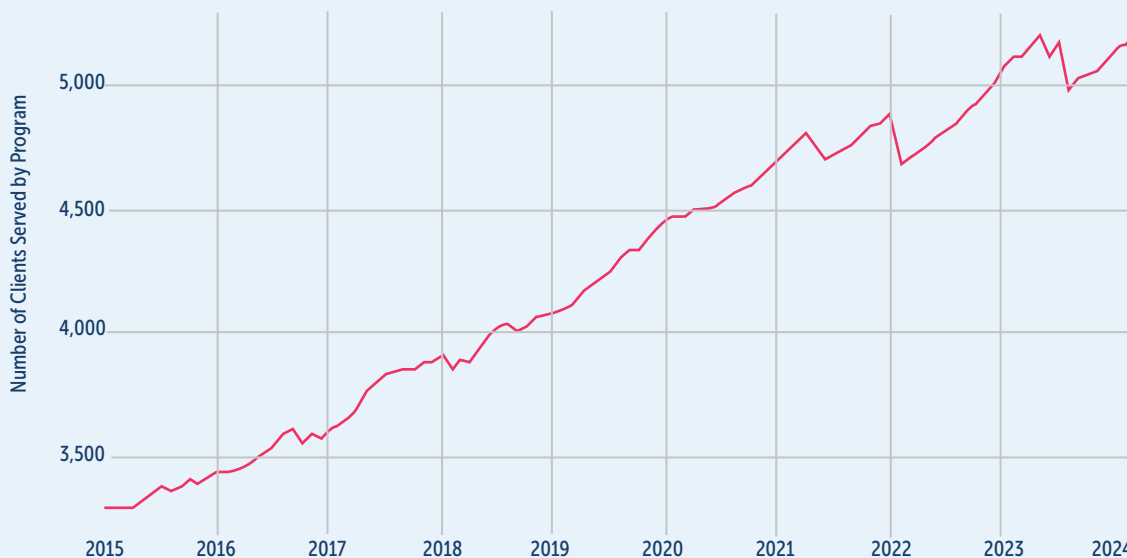


FIGURE 1

Over the years there has been a growing understanding of what is needed to support children with medical complexity. While technology has evolved, the needs of this population have diversified and costs have risen. However, the services and resources available have largely remained unchanged since 1989. Today, children with disabilities and medical complexity are recognized as needing a full range of life experiences to thrive – this includes community participation, functional support and equitable learning opportunities. Yet, despite advances in medicine and technology that improve life expectancy and quality of life, the systemic needs of these children and their families are becoming more complex – but remain under-supported.

Children with medical complexity frequently need access to acute, hospital-based care, and there is a high need for improvement in family-centred, accessible acute care. However, most children with complex conditions spend most of their lives in their communities, being cared for by their families – accordingly, we are focusing in this document on the need for the expansion in funding and investments for family-centred care in homes and communities.

In BC, there are currently a number of programs that provide community and home-based services and care. However, these supports remain fragmented, inequitable, and underfunded across the province. Funding has eroded over time due to a lack of adjustment for inflation and population growth (Figure 1). From a family perspective, much of the funding is designed to feel like a “scarcity model,” where families have to continually prove and re-prove their eligibility, and compete for limited resources rather than designed around entitlement based on need.

For many families, accessing resources is an ongoing cycle of searching for services, fighting for access, adapting their lives to available support, and repeatedly advocating when that access is lost. As a result, the most vulnerable children and youth in the province, along with their already stretched families, lack the support they require. The support these families receive is neither assured, nor equitable, nor consistent across the province.

[IN BRIEF]

CHILDREN WITH MEDICAL COMPLEXITY

Medical and technological advancements over the past few decades have significantly improved survival rates for children with medical complexity, enabling them to live longer.

However, the health and support systems have failed to keep pace with rising costs, growing needs, and rapid population growth.

While these children require extensive healthcare, they also deserve access to a full range of life experiences, community participation, and educational opportunities.

Unfortunately, the support systems meant to enable these opportunities are fragmented, inequitable, and challenging for families to navigate.

Many families, already stretched thin by caregiving demands, are reaching their capacity to manage, leaving them overwhelmed and unable to provide the care their children need to thrive.



The Current Systemic Challenges

Children with medical complexity are beloved members of their families and communities, with dreams, joys, and daily experiences like all children. However, family experiences consistently illuminate how providing care and coordinating the many fragmented supports needed for a fulfilling life becomes an all-encompassing effort for their families.

Despite the existence of numerous guidelines and recommendations (8, 9, 10) for supporting children with medical complexity, these have not been harmonized into policy or systemic reform. As a result, piecing together adequate care remains a continuous and disheartening task, demanding exceptional resilience, resourcefulness, and often, social privilege.

Over the past several decades, various ministries have allocated resources to create a patchwork of programs supporting children and families with complex health needs. When it was created decades ago, the At Home Program was a groundbreaking solution, providing families with access to respite care, therapy, medical equipment, and supplies to support their children at home. Since then, other programs, such as Autism Funding and Nursing Support Services, have been introduced. Additionally, there are foundational services offered through local Child Development Centres, such as Early Intervention Therapy and the Supported Child Development Program for childcare which aim to address other needs.

While each of these programs is meaningful in itself, they are not well integrated, resulting in gaps, unmet needs, and jurisdictional issues within a siloed approach. Families often experience significant flaws within these fragmented services. While a focus on solutions is essential, identifying these systemic issues is a necessary first step toward meaningful change. We have identified nine macro systemic issues, along with their implications for families. At the end, we have included a few examples of how these issues manifest in specific programs – this is not intended to single out these programs, but rather to illustrate some of the most common issues families face in accessing services and care.

The burden of care coordination on families

The current system is a patchwork of programs, funded and run by various ministries, with no meaningful coordination or overarching strategy. This requires families to invest significant personal resources and skills in advocacy, literacy, interpersonal communication, and research just to navigate the “system.” This lack of integration places an overwhelming burden of care coordination on families, forcing them to become experts in navigating complex bureaucratic processes rather than focusing on their child’s care and well-being.

This care coordination may span different ministries, health authorities, school districts



“It has been an extremely frustrating experience trying to navigate (unknown for the most part!) resources. What is available. How to qualify? Once you do qualify, what programs and services can you access? Not to mention the mental toll and stress of having a child with significant support needs. I can’t work anymore and I often feel like I am drowning from the stress. I need respite but it is a massive fight to figure out where to even go – our CYSN social worker says she will advocate but nothing changes.”

Family with CMC



“There are great people out there that want to help, but the systems in place are so disjointed and out of touch. It puts parents into impossible situations that aren’t sustainable. I really do hope change happens in a big way.”

Family with CMC

and CYSN regions, and include tasks such as assembling a care team, scheduling appointments, managing medication refills, ensuring medical supplies and equipment are in place, and planning for home and vehicle adaptations, as well as coordinating a nursing and respite care schedule. Without care coordination support, families are left with the weight of fulfilling every aspect of their child's multilayered care needs. And newcomer families whose first language is not English, and come from different cultural backgrounds, are disproportionately disadvantaged in navigating and coordinating care.

Lack of system capacity due to underfunding

This patchwork system is critically and chronically underfunded. All programs serving children with medical complexity are not adequately funded, including foundational services such as Early Intervention and Supported Child Development Programs. Many families and children are underserved, and even when eligibility criteria are met, families wait unpredictable amounts of time for care. In this context, frontline providers are burdened with overwhelming caseloads, challenging their ability to adhere to professional standards of practice. These issues are further compounded by the challenges in sustaining a robust and skilled workforce for health, social services and education professionals. These issues are not unique to families with medical complexity, but they have a disproportionate impact on these vulnerable children and further marginalizes their families.

Geographic inequities and lack of portability

Some programs supporting children with medical complexity are also challenged by inequitable distribution of funds across the province. Population growth and regional funding allocations are not congruent, leading to long waitlists in some regions while families in other regions receive care.

The disparity in access to care is compounded by geographic inequities in access to care with most centres of expertise located in urban areas. This creates significant gaps in health, community, and family support for those living in more remote or rural regions, leaving many families without accessible, essential services close to home. This disproportionately impacts Indigenous families who are required to leave the cultural safety of their home.

Further to that, many supports are tied to regionally funded programs and completely lack portability. Families who move for work, housing, health or family reasons, will lose funding for services that are regionally allocated like respite and inclusive child care, and face the bottom of a waitlist in their new home community.

Outdated approach to eligibility based on diagnosis or medical need

Inequities are compounded through restrictive eligibility criteria, which differ across

[IN BRIEF]

SYSTEMIC CHALLENGES

The current system is a patchwork of programs, funded and run by three Ministries, with no overarching strategy or inherent equity, trauma-informed or cultural safety approach.

There are multiple significant gaps, with a program-by-program complex, sometimes contradictory approach to eligibility that is not based on the specific needs of CMC.

Even when programs exist, families can be caught between waitlists for availability, geographic inaccessibility, conflicting approaches to eligibility and prioritization, and inequitable allocation of funds.

The disconnections in care are compounded by significant gaps, around care support that would enable family caregivers to work, funding for home and vehicle accessibility and for income support for families who cannot participate in the workforce because of limited access to consistent specialized care.

This leads to financial insecurity and, for many families, chronic stress or mental or physical health challenges.



programs. Eligibility criteria often unintentionally exclude children based on diagnoses, dependency levels, or medical needs—leaving many without support. Programs also use an outdated approach based on diagnosis or medical necessity to determine whether a medical travel benefit, supply, or mobility device will be

Significant gaps in support

This siloed approach and rigid eligibility criteria create significant gaps in support for families – for example a family may be recognized by providers as needing care support, but may be ineligible for one program, waitlisted by another and not prioritized by another. Access is often based not on need but “luck,” the privilege of an English speaking family member being able to advocate for their child, or personal social resources. Similarly, the current funding model for education allows for funds to be diluted or diverted to the greater population of students and results in inequitable school experiences for medically complex kids across different districts.

There is additionally an unmet need for overnight, out-of-home respite as well as other types of agency contracted respite support that help with hiring and training specialized support workers. Some communities have agencies and contracted respite homes that serve this function, but access is inequitable and sparse across the province

Not family centred, trauma informed or culturally safe

This disconnected system inevitably results in a lack of trauma-informed or culturally safe care. The system exacerbates stress for parents and caregivers by failing to recognize them as equal partners on the care team or granting them the autonomy and choice to make decisions about the “who, how, where, and when” of support. This lack of respect and agency is compounded with other challenges families face, including the impact of pediatric medical traumatic stress (11) and systems based ableism (12). Language and cultural barriers, along with socio-economic challenges further marginalize families. Families often interact with professionals who have limited knowledge of disability and medical complexity, further diminishing the quality of care and support.

The fear of engaging with the Children’s Ministry, especially due to its child protection focus, is a significant barrier as many parents worry that seeking help could lead to being perceived as inadequate or neglectful. This concern is further compounded by the reality that CYSN workers, who are themselves under-resourced, may resort to suggesting the extreme option of placing children in care, rather than offering the necessary resources to keep families together. This is particularly relevant for Indigenous families as a result of historic and ongoing multigenerational harms that have been inflicted by this Ministry. The constant re-evaluation of families’ respite and nursing care needs adds to this sense of insecurity, as families fear losing critical support that they rely on for their child’s well-being.



“I am a parent who benefits from a considerable amount of privilege, and it has still been a battle to get my children the supports they need. It’s considerably more difficult for families of more marginalized demographics. It should not be this hard to help our children!”

Family with CMC



“Every time a new parent with a complex infant joins our group and starts asking about income supports because their maternity leave is ending soon, my heart aches for them. I remember being in their shoes, so sure there had to be a program that would allow me to hire consistent help so I could return to work, pay my mortgage, and regain some normalcy. Sadly, my son is now 8, and I’m still his full-time caregiver with very little help. Working, taking vacations, or having any time for myself feels like a distant dream.

Family with CMC

Disconnected from the financial realities of families

Finally, one of the most significant challenges stems from disconnection from the financial realities of families. Families bear the financial burden of extraordinary costs, including accessible home renovations, adapted vehicles, positioning and mobility equipment, and other supports required for daily living. The lack of access to adaptive recreational equipment and programs limits participation in community activities, reducing opportunities for social inclusion and physical health.

Systemic poverty amongst First Nations, newcomers, disabled and single parents means many families and their children go without. In addition, most families experience a loss of income when one parent has to reduce working hours or leave their jobs altogether to provide full-time care and to devote the time necessary to navigate and coordinate care. However, the available income support programs do not account for the unique and extensive needs these families face, leaving many struggling financially while trying to meet their child's medical and caregiving





A Few Common Examples of How These Systemic Challenges Limit Access Continuity, and Care

- ➔ Underfunding means that families who are eligible for respite are placed on long “waitlists,” which are managed through the “Priority for Service Tool” (13). Because of severe funding shortages, this tool allocates limited resources based on urgency, not in the order in which they qualify. This means that families with “lower urgency” can be pushed further down the list by others and cannot anticipate when they might receive services.
- ➔ Families commonly find themselves unable to piece together the care they need, even when they meet the eligibility. For example, a family needing care support outside of school hours may not qualify for Nursing Support Services, be waitlisted for Supported Child Development, and not prioritized for Respite – leaving them with no care. In contrast, another family with similar circumstances may qualify for all three types of support.
- ➔ Specialized Family Services is an obscure, but much needed program that provides nursing support to help families maintain employment – however, it is only available to select families in certain parts of the Lower Mainland who qualify for direct nursing support through Nursing Support Services.
- ➔ Accessible transportation and homes are essential and expensive for both the health and safety of children and their caregivers, but no dedicated support exists. As children grow it can become a prerequisite to having nurses or other hired carers working in the home. The former Giving in Action program (14), which included this kind of support, was discontinued in 2014 and has left a significant void.
- ➔ Clinician recommendations and requests for medical equipment and supplies are frequently dismissed or rejected by adjudicators in the Children’s Ministry, who lack training in health needs. Clinicians also have no direct role in allocating home care or respite support for families, and even when they advocate for a family’s needs in this area, their recommendations are rarely considered. As a result, families are often left without sufficient home care or respite support for their medically complex children.
- ➔ Access to Alternative and Augmentative Communication (AAC) is a fundamental human right. For children with communication challenges, AAC provides tools to express themselves, participate in society, and reach their potential. Currently, SET BC is the only pathway to support in this area, meaning children lack access until school age, and even then, only a handful of kids per district are supported. Funding for preschool AAC programs like Sunny Hill’s “I Can Talk Too” (16) was cut over 10 years ago, eliminating early intervention access.



“We were placed on a respite waitlist, and after a year, I received a voicemail saying we could now access respite. I was so happy. I thought it would allow me to study English and start working. We rent a basement and have to carry our daughter and her wheelchair up and down the stairs, so we hoped this would help us increase our income and move to a more accessible home. However, the social worker explained that the respite was only \$244 a month, enough for just 3 hours of care a week. I’m still not able to work, and we still live in the same basement. I care for my daughter full-time”

— Family with CMC



We don’t have an accessible vehicle, and my son, who is 13 and a full-time wheelchair user, is getting harder to transport. We used to rely on a car seat, but I can no longer transfer him from his wheelchair to the car. Now, we’re essentially stuck at home. His health is fragile, so I don’t feel comfortable exposing him to public transportation. I only take him out for appointments, as accessible taxis are far too expensive for regular outings.

— Family with CMC

The Business Case

The need for a systemic transformation in the support for children with medical complexity and their families in BC is clear. A more coordinated, proactive, and preventative approach to care not only promises better outcomes for families but will also lead to significant financial savings, improved public health, and a more robust and resilient social system. This section outlines the key economic benefits of such a transformation.

Preventative and proactive care: reducing hospital admissions

Shifting from a reactive to a preventative care model for children with medical complexity will dramatically reduce stress for families while also relieving the need for hospital admissions and emergency care. Studies (17) are starting to show that when children with medical complexity receive robust home and community support, and regular, well-coordinated care, family stress is minimized, expensive hospital admissions and emergency visits may be reduced (18).

By providing families with easier community-based access to multidisciplinary care teams—such as nurses, physicians, therapists— and increasing hands-on support for family caregivers, we can collectively manage symptoms, optimize health outcomes, and reduce the burden on acute care services. This shift in care approach will result in long-term cost savings for the healthcare system while improving the quality of life for children and their families

Keeping families together: reducing the need for foster or residential care

One of the most challenging disparities for families with children with medical complexity is that government funding available to foster families is not available to biological families (19). This discrepancy creates a harmful system where some families are either forced to consider placing their children in government care, or having their children removed due to caregiver burnout, mental or physical health crises, or economic hardship.

The emotional, social, health and financial costs of this disparity are profound. Foster care is expensive, and in reality, most children with medical complexity do not find a family placement, but are placed in a residential staffed home – at even greater financial cost. The need for care supports, accessible homes and vehicles, medical equipment, are all accessed easily, as needed, by foster carers while biological families are left to struggle.

Every child has the right (20) to grow up in a family setting, surrounded by love and care, which is crucial to their emotional and developmental well-being. The trauma and harm caused by the absence of this foundational support are considerable, both for the children and their families. These disruptions limit the potential for children



Sadly, my son is now 8, and I'm still his full-time unpaid caregiver with minimal help. At least I'm grateful he's still with me—I know too many families forced to place their kids in foster care due to the lack of support. Ironically, foster families are well-paid, receive respite, and are provided with accessible vehicles.

— Family with CMC

with medical complexity, who demonstrate significantly better health, social, and developmental outcomes (21) when nurtured in strong and stable family units.

By investing in families and reallocating funds in a proactive, preventative way, we can ensure families have the resources they need to sustainably care for their children at home, reduce child removal, and support better outcomes for children.

Supporting families as caregivers and workforce participants: economic benefits

Supporting parents to return to work when possible is not just a moral or social imperative – it is an economic (22) one as well. Parents who have access to adequate respite, childcare, and nursing support are more likely to return to work, which in turn helps families avoid financial instability. This not only provides immediate benefits for families but also contributes to the overall economy by allowing parents to engage in the workforce, pay taxes, and reduce dependency on social welfare programs.

Support must also extend to those who become full time caregivers– recognizing the essential work and specialized skills required to provide and coordinate care for their children is crucial. A robust caregiver benefit or system of family caregiver pay is a critical innovation that would empower families to focus on the long-term caregiving responsibilities that sustain the health and development of their children– filling gaps in the available human resources for care work, while remaining financially stable.

It is important to consider that families need to prepare for the long term financial realities of a child who will likely remain dependent for life, while also saving for their own needs as they age.

Accessible homes and transportation: a vital component of family support

In addition to care support, access to accessible homes and transportation is critical for families of children with medical complexity. Without accessible housing and vehicles, families are forced to make difficult choices regarding their children's care, often compromising their child's health, safety, and mobility – as well as their own. In some instances, home accessibility is a precursor to securing nursing care and other types of home care support. While vehicle accessibility is critical for planning medical travel and for community inclusion, the associated costs can be astronomical, placing additional financial strain on most families and can be completely unattainable for many others.

A dedicated program to support the creation of accessible homes and vehicles would not only improve the well-being of children with medical complexity but also reduce long-term healthcare costs by ensuring that families can safely provide the necessary care within the home. This would allow for greater independence and flexibility for families while also minimizing the need for foster care and group home placements.



"We are surviving, sort of. I have given up on getting any help. The CYSN system is useless, a revolving door of inexperienced social workers who have nothing to offer families unless they are willing to enter a voluntary care agreement. We are not incapable or unwilling to care for our children! Our children need more care than one person can provide. We need real, boots on the ground, hands on, reliable support."

o Family with CMC

Systemic efficiencies: relieving burdens on families and professionals

One of the pressing issues for families is the fragmented system of care, which results in administrative burdens and inefficiencies. Streamlining processes will reduce the time and energy families spend navigating the system, seeking information and coordinating care.

Integrating care pathways—such as a single point of contact for prescriptions, equipment, and care support—would significantly reduce the burden on families and family doctors, who are currently overwhelmed. With primary care in crisis, family doctors and pediatricians are not always equipped to support the intricate needs of children with medical complexity in a typical clinic setting, further underscoring the need for specialized settings and coordinated care.

Specific training and funding models for family doctors, pediatricians and nurse practitioners in caring for the needs of CMC would also go a long way in creating a true system of support across BC.

[IN BRIEF]

THE BUSINESS CASE

Proactive investments will result in clear savings for health and social services, better outcomes for children and better health and wellbeing for families, more efficient and satisfied health and service providers, and greater workforce participation and economic strength.

The investments with the potential for the greatest impact include: preventive healthcare for CMC; family funding that acknowledges the cost of caring for children with medical complexity; system coordination and efficiencies; services that support parental workforce participation; and support for home and vehicle accessibility.

Despite the commitments of frontline providers, the disconnected set of programs puts families into the position of constant self-advocacy and navigation, and generates further trauma and harm, especially for people for whom English is not their first language and for families continually exposed to medical trauma. The challenge is compounded for Indigenous communities with an intergenerational history of harm at the hands of children's ministries.





The Urgent Need for Change: Family Voices

The business case for change is incontrovertible – there are multiple opportunities to create system efficiencies that allow the province to better use its scarce resources. The case for urgent change is exponentially louder when the lives and experiences of families and children with medical complexity are heard.

The current system is not meeting the needs of families or the professionals dedicated to supporting them. Voices across the province — families, frontline professionals, and advocacy organizations — are amplifying the call for change, reflecting the overwhelming demands placed on all who support this population.

Each child with medical complexity has a unique and evolving set of needs, influenced by factors such as age, health status, life stage, and family circumstances. Beyond the statistics, the lived realities of these families are stark. The majority of care for children with medical complexity is provided by family members who undertake intensive, continuous labour to access and coordinate a complex network of supports. Assembling the necessary care and resources is often a daunting, time-consuming, financially precarious, isolating, and exhausting process. For families across the province, challenges are compounded by factors like geographic location, language barriers, and limited social resources.

Navigating this system involves substantial, frustrating labour for families, with complex, costly, and often unnecessary bureaucratic obstacles. Enabling parents to work collaboratively with care teams to self-designate their children's and families' needs would streamline access and relieve much of this administrative burden.

As the previous section outlines, the "system" of care and services does not seamlessly wrap around the needs of children and families. Instead, it is a shifting obstacle course that exhausts and demoralizes those who are most responsible for the care and well-being of one of the province's most vulnerable populations. At best, the system of support is full of significant gaps and has a negative impact on family well-being. At its worst, it contributes to the trauma of each family's experience and forces some families to consider placing their children in care because they cannot access the care, support, and resources they so desperately need. Too often, when families ask the Children's Ministry for help and resources, they are told that nothing more is available and that placing their child in care is the only available option.



"What resonates most deeply with me is the need for a system that recognizes and provides the necessary support for my child and family—without forcing us to navigate complex systems or beg for what should already be in place. It is degrading and humiliating to constantly justify our needs or prove our worthiness for basic assistance. Families like mine shouldn't have to fight tirelessly for support; instead, the system should prioritize dignity and humanity, ensuring that every child and family receives what they need to thrive. A comprehensive, compassionate, and proactive approach to supporting children with complex needs would make the most significant impact, creating an environment where families feel respected and empowered, not exhausted and demoralized."

— Family with CMC

Family voices highlight systemic failures and family hardships

BC Complex Kids Society is hearing from an increasing number of families who have been pushed to the point of filing formal human rights complaints, Patient Quality Care Office complaints, BC Ombudsperson's complaints coupled with increasing advocacy calls to the Representative for Children & Youth in BC (RCYBC), Inclusion BC, BCEdAccess and Family Support Institute. One recent report from BC's Office of the



Human Rights Commissioner (23) and several reports from RCYBC (24) highlight the collective experience and barriers for families navigating the BC system.

Overall, the system fails to recognize the fundamental truth that supporting the child's needs is inseparable from supporting the family as a whole. The lack of integration and the failure to provide consistent, flexible, and comprehensive care leads to unnecessary hardship, and in some cases, pushes families to the brink of considering options like foster care, simply because they cannot access the necessary support to keep their children at home.

This fragmented, contradictory, and inflexible system ultimately harms families and compounds the trauma that many of them are already living with.

[IN BRIEF]

THE URGENT NEED FOR CHANGE

The lived reality for children with medical complexity and their families is deeply challenging, with families forced to spend the vast majority of their time and resources providing hands-on care while also trying to access and coordinate care and services for their children.

The dedicated frontline professionals who provide services are equally frustrated by the complexities of the bureaucracy of the current system.

The system is unsustainable, and families are increasingly insisting that they cannot tolerate the stress and harm of not being able to access essential care and services. Waiting any longer will further compound the trauma that so many are already experiencing.

Because every family's needs are different – and they change as children age or conditions evolve – there is no simple answer. The solution lies in a system where families self-identify their needs and work in partnership with a coordinated, longitudinal care team.



Essential Elements of System Building

SECTION 2

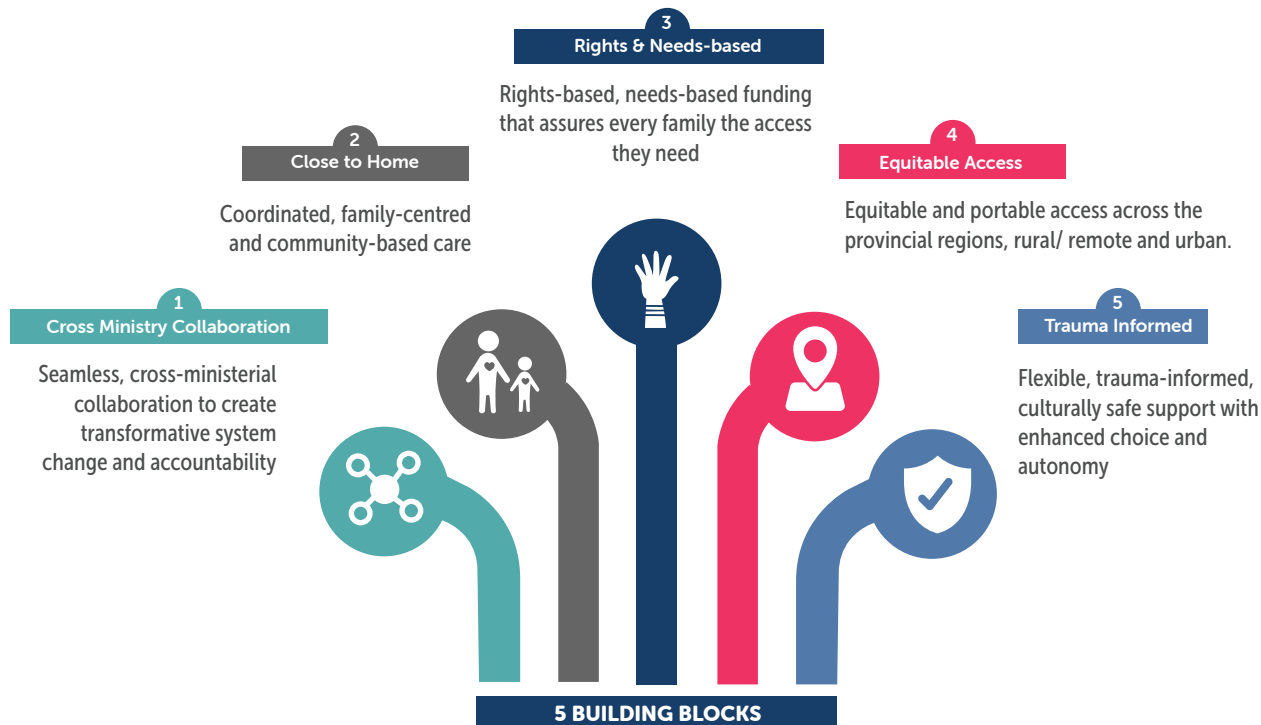
This section outlines the essential elements of system reform, distilled from consultations with families and children, years of studies and assessments, and promising practices in BC and around the world.

Five Building Blocks of a Reformed System

To create a truly effective system of support, several key characteristics and principles must be embedded throughout the design, implementation, and operation of the system. These building blocks are essential to ensure that the system works in a way that is equitable, accessible, and effective for all families, no matter where they live or what their specific needs are.

“One area severely lacking is access to information. Knowing what supports are available to your child WITHOUT asking and BEFORE you’re in crisis and caregiver burnout.”

Family with CMC





1

Cross Ministry Collaboration: Seamless, cross-ministerial collaboration to create transformative system change and accountability.

- ➔ A coherent, cross-ministerial strategy for integrated, family-centred care and services across the province
- ➔ Co-designed systems with families to ensure systems change is respectful and responsive to their lived experiences, and inclusive from the start.
- ➔ Metrics, reporting and appeals processes based on family-defined outcomes to build trust and track system impact.

One of the most significant barriers families face in navigating the current system is the fragmentation of services across different ministries, health authorities, and school districts. This often results in families needing to juggle multiple points of contact, dealing with conflicting policies, and navigating complex bureaucratic processes.

Families need an easily navigable system where they can quickly find and connect to the support they need – not a complicated maze of separate systems, each with its own set of rules and regulations. There could be multiple pathways that lead to a single point of entry, but these should be well-integrated and coordinated to ensure families don't get lost in bureaucracy.

The system must be intentionally redesigned to create a seamless, integrated system of support that is responsive to the needs of children with medical complexity and their families. This transformation will require cross-jurisdictional collaboration and co-design with families and children with medical complexity, based on the principle of "nothing about us, without us."

To shape an equitable, responsive system, we need a collaboration between organizations like BC Complex Kids Society, family partners with lived experience, the various Ministries that support children with medical complexity, community organizations and specialized centres such as BC Children's Hospital and Sunny Hill Health Centre. This participatory approach fosters trust and leads to more effective, relevant, and accessible services, and enables the system to be structured around accountability based on family-relevant outcomes.

Ongoing measurement, transparency, collaboration and adaptation should be built into the new system, enabling continuous learning and evolution based on the feedback and experiences of those who use them.

PROMISING PRACTICE

The province could consider taking the approach of creating a Disability Ministry that creates seamless support across the lifespan. New Zealand provides an example of this approach with the Ministry of Disabled People (25)



"Beyond providing the right supports, the system needs to prioritize dignity, equity, and humanity—ensuring that families are not left feeling exhausted, humiliated, or alone in their struggles. This includes streamlined access to supports, removing unnecessary bureaucratic hurdles, and fostering a culture of trust and respect between families and service providers. Ultimately, the system should not just address the 'what' of support but also the 'how'—delivering services in a way that uplifts families and reinforces their inherent worth and value."

Family with CMC



2 Close to Home: Coordinated, family-centred community-based care.

- ➔ Care coordination teams, to streamline navigation, care planning, and resource allocation, with children and families as partners in decision-making.
- ➔ Extended transition support to provide services for children with medical complexity up to age 25, aiding developmental transitions to adulthood.

Families are best supported in their own communities, where they can access coordinated services that are integrated into their local settings and where they can stay close to family, friends, and their support network. Services should be designed to be close to home to reduce the burden on families who often have to travel long distances to access care, especially those living in rural or remote areas.

Part of having a coordinated system is the extension of care and services to support transitions to adulthood. Transitions are critical for children with medical complexity, particularly as they approach adulthood. Most essential services are cut off at age 18 or 19, leaving gaps in care, social support, and health management while parents scramble to learn a completely new system of support. The current transition environment is complex, abrupt, inequitable and uncoordinated. Specialist care, home care, medical equipment/ supplies and therapy support all abruptly end or change, leaving some youth and their families with unmet needs.

There are significant disparities in the type of support that can be accessed in adulthood, depending on whether or not your child also has a developmental disability along with the physical disability associated with medical complexity. Extending services to age 25 (or across the lifespan when possible) would be very supportive to ensure continuity of care, improved health outcomes, and successful transitions into adulthood. Quality navigation support is also critical but a focus on improving systems to be equitable, navigable and coordinated across ministries and programs, is paramount.

A family-centred care model is essential to ensuring that children and youth with medical complexity receive the support they need while considering the needs of the entire family. This approach recognizes that parents must be equal partners on the care team, with their voices being integral to decision-making. Family driven care ensures that family priorities and strengths are driving care planning processes.

PROMISING PRACTICE

Several jurisdictions are exploring initiatives that enable family caregivers to be compensated for their labour. One promising model is the Certified Nursing Assistant (CNA) program (26) in Colorado, which enables family caregivers to be trained and then compensated as CNAs. This program could provide critical support to families of children with medical complexity, who are often at a breaking point as they strive to earn an income while also juggling the demands of caregiving.



"My oldest is 17 and I am terrified for the transitions coming and for all the support we are losing for his equipment and funding."

— Family with CMC



3

Rights & Needs-based: Rights-based funding that assures every family the access they need.

- ➔ Assured funding so every family has the access they need
- ➔ Needs-based access to support, based on family needs rather than diagnosis or other arbitrary eligibility criteria
- ➔ Ensure each child's unique health and developmental needs are met Rights-based, funding models that address disparities and inflation-adjusted costs.
- ➔ Direct funded support with a family by family approach to ensure choice, autonomy, and portability.

A fundamental pillar of any new system is ensuring that adequate funding is available to meet the needs of families without the obstacles of waitlists, competing priorities, or capped resources. Funding should be assured and entitlement-based, meaning that every child with medical complexity is guaranteed the support they need based on their assessed needs, not their diagnosis or their ability to compete for limited resources.

The funding model should be indexed to inflation to ensure that the system can scale in response to the growing and evolving needs of children and families. It should be budgeted based on evolving demand so that families can access the support they need when they need it, without being delayed or having their needs deprioritized due to lack of funds. Direct funded support with a family-by-family approach will allow for portability, choice and autonomy.

Every child's right to thrive and live with their family, contributing to everyone's health and wellbeing, should be a focal point when building a rights based ecosystem of support.

PROMISING PRACTICE

Rights-based funding is based on the principles outlined in the UN Convention of the Rights of the Child, the UN Convention on the Rights of Persons with Disabilities and the United Nations Declaration on the Rights of Indigenous Peoples, with the goal of ensuring that every child and their family, regardless of their disability, medical complexity, or background, are treated with dignity and respect, are supported to remain together as a family and have access to the same opportunities for well-being and success as their peers.



"I know that our family would benefit hugely from some mental health support. We have had to endure some extremely traumatic medical events and resuscitations. Mental health support has never been offered to us and we are not Okay."

Family with CMC



4 Equitable Access: Equitable geographic accessibility

- ➔ Community-based services, close to home, to reduce reliance on urban-centered programs and ensure localized support.
- ➔ Funding must be equitable across the province and portable across regions

One of the biggest challenges in BC's current system is the disparity in support availability across regions. Families in urban centres often have better access to resources, while those in rural and remote communities are left behind. A well-designed system must provide equitable access to services, regardless of location. The same suite of services — nursing support, therapy, respite, or care coordination — should be available in every community, large or small. Achieving this requires adaptable service models for rural and remote areas, ensuring every family can access core services.

Portability is also critical: families must retain access to services even when moving within the province, including to or from a First Nations reserve. The system should ensure that support follows the family, preventing disruptions when relocating for work, family, or other needs.

[IN BRIEF]

BUILDING BLOCKS OF THE SYSTEM

To build the system that children and families need, and which will enable everyone who works within it to deliver better care, the most foundational principle is “nothing about us, without us.” Beginning with the ideas outlined in this document, families and children with medical complexity need to be part of co-designing programs and services, ensuring that all elements are child and family centred.

The core building blocks of this system include seamless collaboration across ministries, working together to provide adequate funding that assures every family the access they need, based on the right to care, not complicated eligibility criteria.

Because these needs change, funding should be budgeted based on year by year demand for services and allocated with a family by family approach. These supports need to be based in the community, close to home, and need to be equitable across the province, and portable as families move. Choice and autonomy with coordinated & supported decision making will lead to a more trauma

5 Trauma Informed: Flexible, trauma-informed, culturally safe practices

- ➔ Flexible practices that enable families the autonomy and freedom to make informed choices about the care their child receives enabling families to access support in a manner that fits their unique needs and circumstances.
- ➔ Trauma-informed and culturally competent practices that recognize that families come from diverse backgrounds and may have experienced historical or ongoing systems-based trauma.

Autonomy and flexibility are core elements of creating a trauma-informed system, where families are empowered to make informed choices about their child's care and have the space to make appropriate decisions for their unique needs. This includes flexibility in how services are delivered, allowing families to access support in a way that fits their circumstances. It is also essential to integrate practices around anti-racism, anti-ableism, cultural competence, and safety, recognizing that families come from diverse backgrounds and may have experienced historical or ongoing systems-based trauma. Systemic inequities, such as language barriers, can disproportionately affect marginalized communities and must be addressed within the system to ensure equitable support.

Foundational Elements and Promising Practices Present in Today's System

Pockets of today's system already fulfill the intentions behind the five building blocks, and we encourage policymakers to retain and revitalize these as a foundational structure for system reform.

Care Coordination Teams

In recent years, the concept of care coordination teams has emerged as a vital systemic component when supporting children with medical complexity (27). BC Children's Hospital has a small Complex Care Program, established in 2006, that provides care coordination with a limited caseload capacity and limited scope, but has proven the family value of such a service. A Nurse Key Worker is the single point of contact for the broader Complex Care team and supports families in an ongoing and collaborative way with such things as appointment coordination, care planning, supported decision making and provides care continuity.

Sunny Hill Health Centre (28) has recently piloted a Care Coordinator role to meet the overwhelming need but it also has a very limited capacity and scope which stifles its potential for greater impact. They have been supporting diverse and often disadvantaged families, helping them to find their footing and connect to the services, programs and resources they need.





Child Development Centres

The network of Child Development Centres (CDCs) provides essential developmental and therapeutic services to children; these need to be strengthened and adequately funded as non-profit organizations. Over the past several years, this network has been strained and eroded, causing the CDCs to focus on fundraising at the expense of care delivery. Families experience varying levels of both quality and quantity of support from CDC's across the province but their potential remains untapped.

The recent move to fully fund and pilot Family Connections Centres (29) overlooked the opportunity to instead restructure and fund Child Development Centres across the province. It was especially concerning to see a move in one region from community-based nonprofits towards funding for-profit multinational corporations.

We strongly recommend that this system is properly funded as a not-for-profit network. The CDC network can then be strengthened and made a more suitable entry point to services for families in the early years, as they are beginning to navigate the experience of raising a medically complex child. CDC's could either house, or be positioned as a screening, referral and warm hand-off connection point, for the proposed health based care coordination service.

School-Aged Extended Therapy

Another valuable feature of the current system is the School-Aged Extended Therapy (30) direct funding model, which provides a flexible, low-administration pathway for families. Although this model is not perfect, it allows families to choose their therapists from available local professionals, provides assurance of regular therapy sessions, and reduces the bureaucratic burden on families.

Families often find that building a team with the right relational and professional fit is key to success. Offering them the choice to select providers that align with their child's needs would contribute significantly to achieving better outcomes. Moreover, such a choice-driven approach supports the principles of trauma-informed care, as it recognizes the importance of respecting family autonomy and fostering positive, empowering relationships within the therapeutic process.

This model should be preserved and expanded so that At Home Program eligible families have the option to access direct funded therapy services during the critical 0-5 years period. This approach would not only alleviate the burden on overextended CDC's but also empower families with the autonomy to build a therapy team tailored to the specific needs and goals of their child and family.



"I really value Child Development Centres because they're local and accessible, but getting therapy just once a month is nowhere near enough for a two-year-old with a brain injury. Kids at this age need intensive therapy to take advantage of their brain's plasticity and learn how to use their bodies. We're lucky to have great extended benefits that let us afford private therapy twice a week, but I feel for families who don't have that option. The early years are so important, and no child should miss out just because there isn't enough funding"

o Family with CMC



"The At Home Program School Age Therapy funding, now that my children qualify, is amazing. I love being able to hire private therapists that are experts in the things we need and work directly with them and not have to pay upfront. It is truly life changing and this program should be expanded from birth to adult."

o Family with CMC

Flexible Respite Funds

Recent changes have introduced flexibility in how families can use base respite funds, allowing them to hire care for a few hours a week, pay for mental health support, or even cover essential costs like an internet bill so children can access entertainment. While this approach is family-centered and empowering, the funds available are still extremely limited—barely enough to cover a couple of hours a week for a respite worker. Many families are stuck on waitlists just to access this modest amount. If this funding were increased and extended to all families, it could make a far more meaningful difference in their lives.

[IN BRIEF]

FOUNDATIONS AND PROMISING PRACTICES OF TODAY'S SYSTEM

There are several foundations and promising practices in the current system that system reformers can draw on. One of the core elements is the network of Child Development Centres, which needs to be revitalized and fully funded; this network can then be used as an anchor for the implementation of community-based care coordination teams, modeled on the plans for the Slokan Site Redevelopment project.

The School-aged Extended Therapy direct funding model, which provides a flexible, low-administration pathway for families, is an excellent beginning for services that provide continuity of care, family choice and therapy teams that meet the specific needs of children and families.

Flexible Respite Funds provide a model for choice based on family needs, but investment and expansion is needed to realize the potential of this funding model.



Detailed Recommendations

SECTION 3

In the previous sections, we have outlined the current systemic challenges, the need for change, and the essential building blocks and promising practices of system reform. In this section, we provide detailed recommendations for specific change. The first part of this section captures an “acceleration agenda” – three priorities identified by our community of families that can be undertaken right away, with specific options for initiating immediate change.

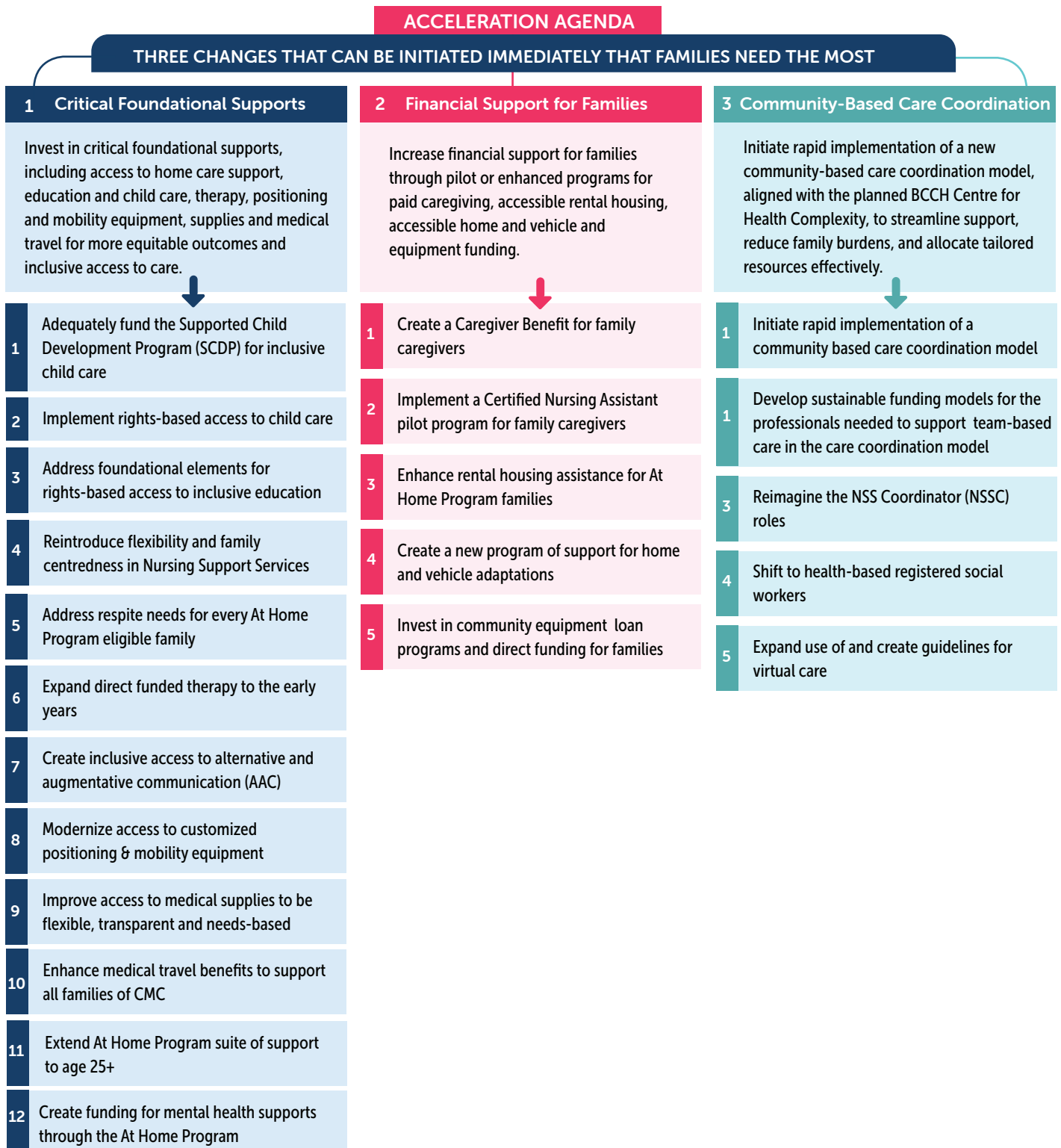
The second part corresponds to the building block of seamless, cross-ministerial collaboration, outlining high level recommendations for long term, systemic transformation.



PART ONE | CHANGES WITH THE GREATEST POTENTIAL FOR IMMEDIATE IMPACT ON FAMILIES

Acceleration Agenda

The “acceleration agenda” identifies three priorities for changes that can be undertaken immediately. This set of recommendations have been prioritized by families as having the greatest potential for immediate family level impact.



1 | ACCELERATION PRIORITY 1 - CRITICAL FOUNDATIONAL SUPPORTS

Invest in critical foundational supports, including access to home care support, education and child care, therapy, positioning and mobility equipment, supplies and medical travel for more equitable outcomes and inclusive access to care.

There are multiple foundational supports that enable better outcomes and greater equity for all children, including therapy, care supports and medical equipment, supplies and medical travel. Immediate investment in these critical supports will vastly improve the lives of children with medical complexity and their families.

1.1 Adequately fund the Supported Child Development Program (SCDP) for inclusive child care

- ➔ Implement a family-by-family, rights based approach, budgeted based on evolving demands, for the support worker funding for child care. This would ensure all families have individualized and fulsome access to portable child care support, including before/after school care and in-home options- negating the need for waitlists and prioritization.
- ➔ Enable families to access funds directly, reducing delays and empowering them to manage their child care needs independently or with the support of their team.
- ➔ Ensure that funding allocations per hour for support workers are adequate and indexed to increase as wages increase.

1.2 Implement rights-based access to child care

- ➔ Adopt a rights-based approach to ensure equitable and inclusive access for all government subsidized early learning & child care programs, including before and after school care programs.
- ➔ Ensure public funding only supports organizations committed to inclusivity and equity, ensuring fair access for all families, and all children.

“[I’ve been] having to work nights due to lack of childcare [due to SCD waitlists] and ruining my health and causing isolation (no friends anymore, no social life, no life outside of care and work). Systems absolutely need to change here. Now.”

Family with CMC

“To know I could have my kids in afterschool care and get a “traditional” 9-5 job again. Which would set my family up for long term success too (savings, retirement, being able to save more in RDSPs for children for future needs etc). I cannot stress enough how life changing these

Family with CMC



1.3 Address foundational elements for rights-based access to inclusive education

- ➔ Address barriers in place that prevent disabled students from being included on field trips.
- ➔ Address school transportation barriers that impact both families and their children.
- ➔ Ensure all school playgrounds are built to a true Universal Design standard to ensure universal access and support for children's right to play.
- ➔ Improve air quality systems to mitigate risks for clinically vulnerable students.

1.4 Reintroduce flexibility and family centredness in Nursing Support Services

- ➔ Restore flexibility in the use of Nursing Support Services (NSS)- Direct Care hours to allow families to better manage their care based on their unique schedules, preferences, and needs and in support of family rights to self-determination and choice.
 - ➔ Restore the potential for families to choose direct funded contracts for nursing services, allowing them to foster relationships with agencies or nurses directly.
 - ➔ Give them access to administrative support to achieve this.
- Introduce new approaches that support recruitment and retention of nurses to the pediatric home care sector– focussing on solutions that benefit nurses will ultimately benefit families.
- ➔ Increase agency oversight including wages, benefits and hours to make the agency positions attractive and equitable with health authority positions.
 - ➔ Consider utilizing the pool of nurses already established in health authorities, with attractive wages and benefit packages already in place.
 - ➔ Address barriers that prevent medically complex students who qualify for direct nursing support from attending school due to a shortage of nurses available to cover school shifts.



"Currently, my child's school has no accessible playing area, or intention to update their facilities at this time. Attempts to include my child in play with their peers during outside time is minimal at best. I had to make a suggestion of what they could do. All playgrounds moving forward should be made accessible from the start to show that all are welcome."

Family with CMC



"We used to be able to use our allocated nursing hours each month to create true respite opportunities for our family. Respite that came in the form of grocery shopping, one on one time with my other child, having a nurse help safely accompany my child to their appointments, and the occasional date with my partner. Now, NSS won't let us use hours in any varied, meaningful, capacity. Need to work outside of school hours? Not their problem. Need to maintain your own mental or physical health? Not their problem. Nurses have cancelled shifts for multiple days and nights in a row? Not their problem. No one can give 24/7 care to a complex child." -

Family with CMC





1.5 Address respite needs for every At Home Program eligible family

- ➔ Fund the flexible base amount of respite funds (\$344/month) for all families raising medically complex kids, to serve the general purpose of 'family support'.
- ➔ Increase the base amount of funding and index to inflation.
- ➔ Eliminate the "Priority for Service Tool" which requires families to prove crisis-level need to qualify for funding and leaves many families lingering on waitlists. Use a family-by-family approach and budget to meet evolving demands.
- ➔ Collect and analyze data on unmet Enhanced Respite needs in BC Service Delivery Areas, ensuring future budgets adequately cover these needs.
- ➔ Explore the unmet need for overnight, out-of-home respite as well as other types of agency contracted respite support that help with hiring and training specialized support workers– current access is inequitable and sparse across the province.

1.6 Expand direct funded therapy to the early years

- ➔ Allow families eligible for the At Home Program to access direct funding for therapies during the critical 0-5 year age period, as an extension of and with the same program approach as the School-Aged Extended Therapy program. This will empower families to build teams with the expertise and relational approach that meets the needs and goals of both the child and family while optimizing resources within the current early intervention system and reducing the therapy caseloads and waitlists.
- ➔ Expand eligibility to include all children with disabilities who require ongoing and long term support from a therapy team.
- ➔ Offer a hybrid approach that allows families to choose between accessing therapy at the local CDC, using direct funded therapy, or a combination of both.

1.7 Create inclusive access to alternative and augmentative communication (AAC)

- ➔ Adopt a rights and needs-based approach to access to the vital supports of Alternative and Augmentative Communication, expanding access to include early intervention and universal availability as AAC provides the tools for children to express themselves, participate in society, and achieve their full potential.
- ➔ Expand the capacity of SET-BC to support children in the preschool years, as no support exists now. Historically, Sunny Hill Health Centre delivered a program called "I Can Talk Too" (16) but funding was cut more than 10 years ago.
- ➔ Expand the capacity of SET-BC to fully support all children in the education system who require AAC technology and support, as current capacity limits access to a handful of students per district.



"Having equitable access to respite is huge. Instead, we are told to call consistently complaining about our days to 'prove' how challenging they are and how much crisis and trauma we are enduring. Not a great fit for my personality and just trying to survive doesn't leave a lot of time and energy for 'begging' for help."

Family with CMC



"We are told that early intervention is key yet we are waitlisted for months, even years for crucial services."

Family with CMC



"We didn't qualify for charity and couldn't afford a brand new iPad and \$400 AAC program when my child was a toddler, despite it being highly recommended by her SLP for her development. Now she is in grade 3 and playing catch up with the schools device (can't bring it home), learning something we should have had access to all along."

Family with CMC



1.8 Modernize access to customized positioning and mobility equipment

- ➔ Move to a modernized model of equipment provision and remove the current mandate of 'medical necessity' from the policies for equipment provision to improve child and family well being, health and participation.
- ➔ Use the International Classification of Functioning, Disability and Health (ICF) and the F-Words (6) to provide positioning and mobility equipment (including options and features) that support activity and participation in community and family life.
- ➔ Move to a system that is respectful of the professional justifications provided by therapists during the acquisition process to ensure decisions are clinically informed—resulting in less workforce burnout and inefficiencies from repeatedly dealing with equipment denials and the inordinate amount of time and energy spent navigating the charity landscape for alternative funding.
- ➔ Index any and all funding cap amounts to inflation.

PROMISING PRACTICE

The Special Services At Home Program (31) in Ontario provides funding for family support, including support for disabled children to participate in activities at home or in the community. Eligible expenses include items or services that support a child's goals around Functioning, Family, Fitness, Fun, Friends, Future - the F Words! This child and family centred framework is based on the International Classification of Functioning, Disability and Health, and provides a positive, strength based approach to health and development.



"Fighting the system and all the "paperwork" and emails is a full time job for a tired mom who also works outside the home in order to survive/pay bills/etc. I shouldn't have to fight for a wheelchair for my son. Why do I need to prove the need for medical device? And then at the same time can't afford to make our house wheelchair usable and can't afford to move. Just one example of trying to make my son life better with so many barriers."

Family with CMC





1.9 Improve access to medical supplies to be flexible, transparent and needs-based

- ➔ Revise policies to remove the requirement that medical supplies must be directly related to the “diagnosis on file” and instead, medical supply decisions should be needs based.
- ➔ Requests made by healthcare professionals should be respectfully reviewed and promptly approved to reduce delays as clinicians are the best positioned to understand the specific needs of their patients
- ➔ Implement an electronic portal system to streamline ordering, allow for real-time updates, to improve transparency and communication with families—enabling parents and care team members to view and manage supply orders, request additions, and track approvals and shipments, staying better informed and thus relieving the burden of needing to track down updates etc.

1.10 Enhance medical travel benefits to support all families of CMC

- ➔ Remove the requirement that medical travel benefits be tied to a specific diagnosis, recognizing that children with complex medical needs often have multiple, intersecting conditions that require ongoing, specialized care at BC Children’s Hospital.
- ➔ Expand medical travel benefits to include parking assistance at any hospital in the province, for families who face recurring financial strain from parking fees during frequent hospital visits.

1.11 Extend At Home Program suite of support to age 25+

- ➔ Extend support for the At Home Program and other home & community level supports, to at least age 25, or across the lifespan, to provide continuity during transitions to adult care, ensuring stable support during this key life stage.

1.12 Create funding for mental health supports through the At Home Program

- ➔ Ensure families have access to mental health supports, such as funding for counselling services and peer-to-peer support, for the medically complex child, siblings and parents. Medical traumatic stress (11) is a significant burden on families and having access to mental health care before crisis, after traumatic hospitalizations, and throughout ongoing navigation of this uncertain life is critical. This funding could be distributed as an extension to SAET, to all eligible families on the At Home Program.



“Travel medical expenses [should] include other municipalities other than GVRD — for example, parking at Kelowna General Hospital (and elsewhere) is not free and certain complex kids are there frequently.”

Family with CMC



“The transition to adult supports is severely lacking. The gap between the ages of 18 and 19 is unacceptable and leaves families in crisis and their child at risk.”

Family with CMC



“Many families caring for children having life threatening diseases aren’t prepared or have the proper support or even recognition that this too, falls in the realm of palliative, with many unknowns...[we need] proper trauma support for families such as first responders get. Try to prevent PTSD and other major mental [health] issues.”

Family with CMC

2 | ACCELERATION PRIORITY 2 - FINANCIAL SUPPORT FOR FAMILIES

Increase financial support for families through pilot or enhanced programs for paid caregiving, income support, accessible rental housing assistance, accessible home and vehicle funding and access for other unmet equipment needs.

There are several opportunities to create pilot programs or enhance existing programs to increase financial support for families.

2.1 Create a Caregiver Benefit for family caregivers

- ➔ The creation of a non income tested, non-taxable, Caregiver Benefit to provide financial assistance for family caregivers of medically complex children is a long awaited and much needed innovation for families struggling to make ends meet.
- ➔ Quebec has a system of financial support that provides up to \$1500 per month (32), depending on the complexity of the child's care needs. The two tier system is accessed by a thorough application process that is reviewed by a small team of health professionals who take into account all relevant health information and the daily care needs of the child.
- ➔ It is critical that a caregiver benefit works in conjunction with any other provincial or federal benefits and is not clawed back, while also being indexed



"This is a huge missing gap that would drastically improve the well-being of families with complex needs children. I cannot emphasize this enough as parents are often the most skilled in caring for their children and are unable to return to work because of the complexity of needs."

o Family with CMC

2.2 Implement a Certified Nursing Assistant pilot program for family caregivers

- ➔ Pilot a Certified Nursing Assistant (CNA) program (26) (or other similar model) that provides hourly wages and benefits to family members who are trained and certified to act as nursing assistants for their medically complex children. This program would help address labor shortages in the healthcare sector, empower families as active partners in care, and alleviate financial strain on families—particularly mothers—who often perform unpaid caregiving.
- ➔ By supporting families in this way, BC can reduce the financial instability and poverty associated with intensive caregiving responsibilities, while also creating a stable and skilled care network for children with medical complexity. Such a program could also be used to increase the home care workforce for children who do not need the judgement of a nurse but require specialized care support in the home.
- ➔ Eligibility criteria should extend beyond the population currently eligible for Nursing Support Services. The Certified Nursing Assistant program in Colorado uses a "standardized assessment tool that identifies needs for activities of daily living assistance and medical tasks. Examples of medical needs relevant to eligibility include supplemental oxygen, secretion management, tube feedings, and repositioning to prevent skin breakdown."

PROMISING PRACTICE

In Quebec, parents of children with medical complexity may receive up to \$1500 per month financial assistance. Applications are assessed by a small team of health professionals who take into account all relevant information provided by the child's healthcare team. The monthly amount is not income tested or taxable and is indexed to inflation.



2.3 Enhance rental housing assistance for At Home Program families

- ➔ Increase the amount of support for At Home Program families through the Rental Assistance Program (33) to acknowledge the monthly costs associated with finding an appropriate rental for accessibility needs.
- ➔ Increase availability of accessible subsidized and co-op housing, to meet the needs of families raising medically complex children.

2.4 Create a new program of support for home and vehicle adaptations

- ➔ Leverage insights from the Giving in Action Fund (34) evaluation to develop a comprehensive program that ensures all families, regardless of income or assets, have individualized and holistic support to address the accessibility needs of their child and family.
- ➔ This program would cover essential adaptations such as wheelchair ramps, accessible bathrooms, widened doorways, vehicle lifts, and secure seating systems, enabling families to safely and effectively care for their children within their homes and communities.
- ➔ Include professional support and assessments to guide families in planning these adaptations effectively, ensuring each setup meets the specific accessibility and safety needs of the child and family.
- ➔ Allow broader access to the Rebates for Accessible Home Adaptations (35) program by doubling the asset limit to \$200,000 and removing the Home Value Limits from the eligibility criteria. This would serve as a temporary measure that would be supportive while a robust program of accessible home and vehicle accessibility support is created.



"It took over 1.5yrs to get a bike, 1yr to get a new wheelchair, and what do we do with our outgrown stuff we got ourselves. A loan program would make it so much faster and have access to more types of equipment."

— Family with CMC

2.5 Invest in community equipment loan programs and direct funding for families

- ➔ Invest in a loan program and/or create a family funding mechanism for essential tools and resources, enabling families to access the equipment and support they need quickly and as children's developmental needs evolve.
- ➔ Types of equipment needed include: Alternative and Augmentative Communication (AAC) equipment, developmental tools and toys; early years - positioning & mobility equipment and adaptive recreation equipment. Not to duplicate the CMEDS equipment loan pool.



3 | ACCELERATION PRIORITY 3 - COMMUNITY BASED CARE

Initiate rapid implementation of a new community-based care coordination model, aligned with the planned BCCH Centre for Health Complexity, to streamline support, reduce family burdens, and allocate tailored resources effectively.

One of the foundational transformations that would make the biggest difference for families and children with medical complexity is the expansion of coordinated care models across all BC communities.

3.1 Initiate rapid implementation of a community-based care coordination model

- ➔ Implement a prototype, community-based care coordination model, aligned with the service model planned for the future BCCH Centre for Health Complexity.
- ➔ Initiate this model now to integrate the service with pending CYSN service delivery changes and to test, adapt and refine the approach while the Slocan Site Redevelopment Project is underway
- ➔ Prioritize bringing services 'close to home' to address geographic barriers faced by families in rural, remote, and underserved regions.
- ➔ Establish the core role of a Nurse Key Worker as part of a team-based care model to assist families by providing care coordination. On Page 42 we propose a possible pathway for implementation.

3.2 Develop sustainable funding models for the professionals needed to support team-based care in the care coordination model

- ➔ Develop funding models that ensure sustainable, team-based care by supporting core roles such as nurse key workers, administrative support staff, health-based registered social workers, parent partners, pediatricians, family doctors, nurse practitioners, dieticians, therapists, and mental health professionals.

3.3 Reimagine the NSS Coordinator (NSSC) roles

- ➔ Shift responsibility and direct oversight for these roles to BC Children's Hospital to align this service with the emerging care coordination model and reduce cross-jurisdictional challenges, enabling consistent support for families.
- ➔ These NSSC roles could then be reimagined and tasked as the Nurse Key Workers– the central role for building teams of community support, close to home, for children with medical complexity.



"It would be hugely beneficial for families to have a pediatric care navigator that can help with transitions between BCCH, Sunnyhill, local health authorizes, pediatricians, school aged therapies and IDP's. I cannot even guess as to how many hours I have invested into trial and error of investigating programs, qualifications, and if these programs are actual or just listed on paper. Nothing is offered to families. You must find it for yourself."

— Family with CMC

3.4 Shift to health-based registered social workers for CMC

- ➔ Assigning medically complex children to health-based Registered Social Workers instead of MCFD's Children and Youth with Support Needs (CYSN) caseloads would create a trauma-informed and supportive approach, ensuring that families receive care through a combined health and social lens, with increased accessibility, responsiveness and accountability
- ➔ Benefits also include alleviating the caseload pressure on CYSN workers, allowing both systems to operate more effectively and improve care continuity for all populations.

3.5 Expand use of and create guidelines for virtual care

- ➔ Expand appropriate, relational family-centred use of virtual care (37, 38), to enable better use of resources, minimize travel for families, and open the door to more responsive support from care coordination teams including symptom management, virtual therapy appointments, team care planning meetings, and mental health support.





CARE COORDINATION: POSSIBLE PATHWAY FOR IMPLEMENTATION

One practical pathway to establish a community-based care coordination service would be to build on existing roles, including Nursing Support Services Coordinators (NSSC) who could take on an expanded role as Nurse Key Workers. With the addition of a health-based registered Social Worker role and the support of an Administrative Support role, this service could be implemented rapidly.

This new team could be housed in public health spaces or in Child Development Centres with new integrated service pathways to ensure ease of access to a single point of entry. In the first three years, this team would grow to include the members listed in Recommendation 3.2 and support the local delivery of the following elements, across all health, education and social care domains, specifically for families identified as raising children with medical complexity:

- ➔ **Population Identification:** Identify and connect families to the care coordination service.
- ➔ **Needs Assessments:** Conduct assessments using a standardized tool like the interRai Child and Youth Pediatric Home Care instrument (39).
- ➔ **Diagnostic Support:** Prioritize early access to diagnostic processes like genetic testing, cerebral palsy diagnostics, and autism assessments.
- ➔ **Care Coordination:** Support navigation, appointment coordination, care planning, mapping and shared decision making.
- ➔ **Peer Support:** Connect families with local networks and peer support systems.
- ➔ **At Home Program:** Support program delivery.
- ➔ **Nursing Support Services & Certified Nursing Assistant Program:** Provide the training, assessment and delivery of these programs.
- ➔ **Symptom & Pain Management:** Provide support through virtual care and home visits.
- ➔ **Mental Health Support:** Ensure mental health services are available for families.
- ➔ **Home & Vehicle Modifications:** Offer planning and resourcing support.
- ➔ **Palliative Care:** Expand localized support in partnership with Canuck Place Children's Hospice.
- ➔ **Transition Support:** Support transitions from hospital to home, preschool to elementary school, highschool and from pediatric to adult services.
- ➔ **Equipment Loan:** Provide an array of equipment available for loan.



PART TWO | RECOMMENDATIONS FOR SYSTEM TRANSFORMATION

The “recommendations for system transformation” identifies several high level priorities that would enable better systemic support systems for long term systemic transformation.

But first we offer a foundational recommendation that we see as an essential anchor for the work ahead. Families and professionals who are intimately familiar with the strengths and failings of the current system, hold the knowledge and experience to guide BC to a future where children with medical complexity and their families can move beyond survival.

FOUNDATIONAL RECOMMENDATION

Create a strategy for seamless, cross-ministerial collaboration, co-designed with families and children with medical complexity.

The most fundamental recommendation is to convene a cross ministry, cross sectoral table of stakeholders to create a shared, coherent strategy for system change that incorporates the essential building blocks needed by families and children with medical complexity. This collaborative work should support truly transformative, systemic change, with the goal of a robust pool of resources and an interconnecting network, as no single policy change or innovation will be impactful or result in equitable care.

Essential stakeholders include parent partners, community organizations and an array of front line professionals and program managers who are intimately familiar with the current systems landscape and have a vested interest in the success of a new model. Special attention should be given to ensuring representation of multiply-marginalized populations – Indigenous, newcomers, rural/ remote, impoverished, single parents and those with disabilities of their own. Prioritizing system design for those who have been historically marginalized will help mitigate unintended consequences and prevent future harm.

The overarching strategy should include enabling structures that will guide system change and sustainable policy and practice.



“These larger systemic recommendations resonate strongly with me, particularly the emphasis on creating a system that proactively provides necessary support to children and families without placing the burden on us to navigate complex, degrading processes.”

o Family with CMC



Recommendations for System Transformation:

This section identifies several high-level priorities that would enable better systemic support systems for long-term transformation. The recommendations fall within five broader areas, including improving financial security for families, child care and early intervention, structural shifts, and embedding disability rights.

- Financial Security for Families
- Health and Education System Capacity
- Structural Shifts
- Embedding Disability Rights.
- Child care and Early Intervention

1	Create a targeted income support and poverty reduction plan	2	Revitalize the network of Child Development Centres	3	Address workforce needs through education, investment and innovation
4	Build capacity for caring for CMC across health professions	5	Address delegated nursing support challenges in the education system	6	Provide enhanced training and pay for education assistants
7	Develop a team-based, child-centred education model	8	Improve funding levels in schools to ensure appropriate support	9	Expand provincial child care with a rights-based approach
10	Fully fund early intervention and foundational programs	11	Shift the At Home Program to the Ministry of Health	12	Build transparent accountability structures around family-defined outcome
13	Incorporate the principles and obligations of UNCRPD into provincial policies	14	Establish a Provincial Disability Office	15	Expand the mandate of the Representative for Children and Youth
16	Explore the potential of implementing a disability insurance plan in BC				

**A Improving Financial Security for Families****1 Create a targeted income support and poverty reduction strategy**

- ➔ Initiate research and jurisdictional scans aimed at developing a targeted income support and poverty reduction strategy for families raising medically complex children. This aligns with the “problem area that needs attention” (40) identified by the Representative for Children & Youth in the 2020 “Left Out” report.
- ➔ Work with key ministries to develop a detailed, actionable plan. This plan should focus on the unique financial burdens these families face, and the need for accessible home and vehicle adaptations, specialized care support and income support.

B Health and Education System Capacity**2 Revitalize the network of Child Development Centres**

- ➔ Fully fund the essential network of Child Development Centres as a foundational non for profit community service, enabling them to focus on service delivery instead of fundraising.
- ➔ Position CDCs as one of the main systemic entry points for families. By having clinical professionals on-site who can conduct initial screenings, CDCs can help ensure that children are connected to the appropriate resources and service pathways based on their specific needs.

3 Address workforce needs through education, investment and innovation

- ➔ Address skilled workforce shortages across the rehabilitation sector, through prioritized education and innovation. Increase the integration of therapy assistants and rehabilitation assistants into the workforce– supporting the delivery of therapies under the guidance of licensed clinicians, thus helping to increase capacity in areas with a shortage of specialized professionals.
- ➔ Address the need for a highly skilled workforce of: Early Childhood Educators, including inclusion support workers, education assistants, home care support workers and nursing assistants. New educational pathways with standardized educational and skills outcomes, would support a new workforce and desirable employment opportunities.

PROMISING PRACTICE

BC previously had a funding opportunity called the Giving in Action program (41) that had demonstrable benefits for both the economy and for the well-being and health of families. It provided funding for both home and vehicle adaptations. When the funding evaporated it left a “generally negative impact on the sector and a disproportionately negative impact on low and middle income families, and families in rural BC.”



4 Build capacity for caring for children with medical complexity across health professions

- ➔ Enhance training and education in the care of children with medical complexity for family doctors, pediatricians, nurse practitioners and nurses, within initial education and at the community level for people already in practice.

5 Address nursing support challenges in the education system

- ➔ Address the ongoing challenges in child care and education settings for children who require direct or delegated care support to attend
- ➔ A focus on family centredness and children's rights must be at the forefront while navigating the regulations and limitations of each jurisdictional body involved. Structural and regulatory changes should be considered.

6 Provide enhanced training and increased remuneration for education assistants

- ➔ Standardize and enhance training programs for Education Assistants (EAs), focusing on skills for working with children with complex medical and/or behavioural challenges.
- ➔ Increase Educational Assistant pay to improve recruitment, retention, and job satisfaction. Adequate pay acknowledges their contributions and ensures continuity of care and support for students, fostering long-term relationships.

7 Develop a team-based, child centred education model

- ➔ Invite privately hired therapists, behaviour analysts, and other professionals to collaborate directly with school-based teams on intervention planning and support for children. Current restrictions lead to high caseloads for district-employed specialists, reducing the quality of care. Including external professionals and families, enhances the consistency and effectiveness of support for students.

8 Improve funding levels in schools to ensure appropriate support

- ➔ Increase funding levels to ensure schools can provide appropriate support for all students, especially those with medical complexity and disability. Adequate resources enable schools to hire specialized staff, invest in training, and provide individualized support as needed.
- ➔ Ensure that targeted designation funding is allocated to the intended student's needs.
- ➔ It is equally critical to maintain equitable funding levels, support and access to Online Learning for families who choose this education pathway, when they are not served by the bricks and mortar education system.



"Although there's funding allocated to school districts from the Ministry of Education to support inclusion, it's hard to really track. One, if that is enough money to meet the needs of the district, and two, how is it being utilized to support the inclusion of individual students? Because although the designation is attached to the student, the funding doesn't go directly to that student. It goes to the school district to use as a pool to create inclusive opportunities for students with disabilities or support youth in their learning."(42)

— Karla Verschoor,

Executive Director of Inclusion BC
in an interview with Global News



C Child Care and Early Intervention

9 Expand provincial child care with a rights-based approach

- ➔ Provincial child care expansion, supported by the Canada-Wide Early Learning and Child Care program, must happen within a framework of intentional policies and commitments that prioritize the rights of disabled children who are too often excluded.
- ➔ Important considerations include universal design in the built environment, appropriate ratios and staffing models and barrier free funding models for both families and child care providers.

10 Fully fund early intervention and foundational programs

- ➔ Invest and build capacity in the publicly delivered foundational programs to support the system to be more responsive and better able to provide timely and adequate community based support in the early years and beyond.



“Children can’t put their age on hold. Thousands of children and youth with intellectual and developmental disabilities in British Columbia sit on waitlists for urgently-needed therapies, supports and services. Many never get the help and support they need because they age out of systems before they reach the top of the list. Our goal is to make sure early intervention and education systems are well-funded and easily accessible.” (43)

— Excerpt from

Inclusion BC website referencing
Kids Can’t Wait campaign



**C Structural Shifts****11 Shift the At Home Program to the Ministry of Health**

- ➔ Consider moving the At Home Program from the Ministry of Children & Family Development (MCFD) to the Ministry of Health– with an aim to streamline access to essential health-related supports like therapy, medical equipment, medical supplies, and tailored respite and home care– reducing cross-jurisdictional challenges, enabling clinically informed decisions and supporting trauma-informed care.

12 Build transparent accountability structures around family-defined outcomes

- ➔ Build transparent appeals, complaints, and dispute processes into the system, ensuring that families can easily voice concerns and seek redress in a timely, responsive, navigable, and supported process.
- ➔ Learn from family complaints and feedback to drive positive change by incorporating solutions-based approaches that focus on resolving issues, rather than creating more obstacles and consistent work towards improving systems.
- ➔ Build transparent and accountable data-collection and sharing– keeping families informed about how their information is being used and have the ability to track the progress of their case or request.

D Embedding Disability Rights**13 Embed the United Nations Convention on the Rights of Persons with Disabilities into policy in BC**

- ➔ Embedding rights into policy would create a framework ensuring that the rights of individuals with disabilities are enshrined in provincial laws, guaranteeing the right to appropriate and adequate support across their lifespan.
- ➔ This should include rights-based funding as defined by UN conventions for Children, Disability Rights and Indigenous Rights.

14 Establish a provincial disability office with a lead Disability Advocate

- ➔ With a mandate to monitor and report on disability rights across sectors, ensuring rights-based access to resources and services
- ➔ The lead advocate mandate should include making recommendations to improve cross ministry coordination, easing access to holistic support for people with disabilities.
- ➔ Set up regional offices to ensure localized monitoring and equitable access to services, addressing disparities in availability and quality of support.

15 Expand the mandate of the Representative of Children & Youth, as recommended by the Select Standing Committee for Children & Youth (44)

- ➔ To include Nursing Support Services and the assessment and diagnostic clinics for children with Autism (BC Autism Assessment Network) and complex behavioral disorders (Complex Developmental Behavioral Conditions Network) funded by the Ministry of Health or health authorities; and
- ➔ To include special (inclusive) education services funded by the Ministry of Education and Child Care for children and youth who are currently receiving services for children and youth with support needs.

16 Explore the potential of implementing a disability insurance plan in BC

- ➔ Explore the potential of implementing a disability insurance plan (DIP) in BC, modeled after Australia's National Disability Insurance Scheme (NDIS) but with a distinctly "made in BC" approach and incorporating the learnings from the recent NDIS review to ensure the system is equitable, sustainable, and accessible to all individuals with disabilities.



It is without question in our mind that the role and work of the Representative's office continues to be necessary. We also believe that an expanded mandate would allow that work to grow even deeper in the areas of greatest concern to our demographic. Systemic reform for CYSN has been ignited, in large part due to the work of the Representative and her team and the work of this committee but that work is only just beginning and certainly needs oversight and guidance as families are deeply concerned about the future of those systems."

Excerpt from the
BC Complex Kids Society submission
on the mandate review (43)



Final Note

As BC Complex Kids Society collaborated to create this document, we always had the voices and experiences of families and children with medical complexity at the centre. As part of the process, we shared the near-final draft with several members of our community and asked for their feedback. We were affirmed to hear that our work matched our community's needs. Some of the comments include:

"These are excellent, deeply connected, and well thought out ideas that manage to capture a very broad range of need in an incredibly diverse group of parents and children. I have taken part in many surveys for CYMH/CYSN consultation process and this is the only one that comes close to capturing the picture of our support needs. Thank you Brenda & Co. For knowing your community. It shows."

"Amazing. Truly thoughtful, designed around equity, and for me personally, would be life changing to know I could have my kids in afterschool care and get a "traditional" 9-5 job again. Which would set my family up for long term success too (savings, retirement, being able to save more in RDSPs for children for future needs etc). I cannot stress enough how life changing these recommendations would be... especially childcare, home adaptations, and adequate medical device coverage."

"This is tremendously well-done work. Thank you so much for putting a tremendous amount of time to research and compose such a comprehensive, in-depth and professional work, knowing you are a family for a child with medical complexity too. We often are too exhausted to advocate. It is empowering to read. I have nothing to say but thank you. thank you. Amazing work again. With gratitude."

"These recommendations are very clear and well thought out. I appreciate the opportunity to share my feedback and opinions on this subject."

"Thank you for this. I feel seen."

Acknowledgements

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Cate Creede-Desmarais with The Potential Group was an instrumental support for the whole process, from early development to our final report. We are deeply appreciative of the support, insight and expertise she shared with our team.

Thank you to the Government of BC for funding and providing the opportunity to present this report and recommendations.

BC Complex Kids Society respectfully acknowledges that we live and work on ancestral, traditional and unceded Indigenous lands.

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"Advancements in medical technology have saved our kids' lives but there's a cost to us and to the rest of our families as we care for them. If tiny and fragile babies are going to survive, we need to build a system that will support their living."

— Family with CMC

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